

## **BHIVA Standards of care online consultation comments**

**7 October 2012**

### **Standard 2: Access to, and retention in, HIV treatment and care**

**18 September 2012**

**John Evans-Jones sent the following message:**

Re Transfer letters : some services obtain written consent to disclose - is this necessarily required ?

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**2 October 2012**

**Hilary Curtis from BHIVA clinical audit coordinator sent the following message:**

While I strongly agree with auditing the proportion of people with known HIV infection who have accessed clinical services within the past 12 months, I'm a bit uncertain about the suggested 90% target. Does it have a sound basis? We know from HPA data that the loss each year is around 5% but some of those subsequently come back. The long term retention rate is thus a complex dynamic mix of those leaving and those returning. I am not convinced there is good evidence on which to set a target.

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**2 October 2012**

**Allan Anderson from Positively UK sent the following message:**

Overall Positively UK welcome the standard as it is, but would recommend the following be included:

Retention in Care: the Quality Statements identify that anyone who is 'unhappy with the care provided' be offered another clinician or referral to another clinic. Dissatisfaction with clinical care nor are mechanisms to identify this, included in the relevant paragraph on page 2 'People may fall out of specialist HIV care...'. We recommend the inclusion of wording such as 'systems should be in place to assess patient satisfaction with clinical care to assess where this may be the cause of loss of retention, and appropriate action taken.'

Access: We welcome statements about giving patients information about their condition, CD4 count, therapies etc, and this complements and supports Standards 9 and 10 promoting meaningful involvement of plhiv. Positively UK's experience demonstrates that one of the biggest obstacles to people newly diagnosed fully coming to terms and understanding HIV is access to basic information about HIV, how it affects the body, what is a CD4 count or viral load is. This section should include 'People who have a new diagnosis should have access to basic information about HIV, written and/or through peer and community support'.

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**4 October 2012**

**Sarah Barber from Bromley Healthcare sent the following message:**

see a specialist within 24 hours if symptoms.

Do you need to expand this as with 50% of patients presenting late, many patients have symptoms but not many are so severe that they would need to be seen within 24 hours.

Perhaps be a bit more specific about what you mean.

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**5 October 2012**

**Roger Pebody from NAM sent the following message:**

Under rationale, retention in care, paragraph 2: "People may fall out of specialist HIV care for a variety of reasons..." This paragraph then focuses on problems with the patient, rather than problems with the service. How about adding: "Some services are harder to access and less welcoming than others." Also, please add just before the point on transfer arrangements: "Mechanisms should be in place to encourage retention and engage with patients who miss appointments."

Quality statements, retention, second one. "Follow up" people is unclear. How about "re-establish contact"?

Auditable outcomes: Need an outcome on accessing care following testing in a community setting.

Please add as an auditable outcome: "Evidence of referral pathways to emotional, psychological and peer-support services."

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**6 October 2012**

**Dr Fiona Thompson from CHIVA sent the following message:**

As previously discussed in Manchester, please could we have a paragraph about transition in the Access to Care section along the lines of:

'Transition of young people with HIV infection from paediatric services should be effective and planned with each young person having an individualised plan of transition in line with CHIVA and HYPnet guidance'

Thank you

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**7 October 2012**

**Dr Olufunso Olarinde from South Yorkshire HIV Network sent the following message:**

Standard 2

People newly diagnosed with HIV, wherever they are tested, should have access to a full assessment carried out by appropriately trained practitioners with specialist expertise in HIV at the earliest possible opportunity and no later than 2 weeks after receiving a positive HIV test result

Comments:

Will 4 weeks be more practical as this would allow inclusion of those who remain on a ward for some time?

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**7 October 2012**

**Clare Stradling from DHIVA sent the following message:**

for section in Rationale, insert:

multi-disciplinary

including allied health professionals

“ Mechanisms must be in place for seamless transition of care, both from the sending and receiving clinical services, with appropriate transfer of information between multi disciplinary teams including allied health professionals”

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**7 October 2012**

**Lindsay Short from Calderdale and Huddersfield NHS Foundation Trust sent the following message:**

Retention in care can be particularly challenging in areas where there are asylum dispersal and reception centres. People are moved at short notice with no information on where they have been dispersed to. Some way of improving this situation would be very helpful and allow continuity of care. There is often a delay in finding out that a patient has been removed to a detention centre. Greater understanding by the immigration authorities would help with this difficult problem.

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**7 October 2012**

**Jacqueline Stevenson from African Health Policy Network (Ffena) sent the following message:**

In addition to “HIV-appropriate emotional, psychological and peer-support services” individuals may also benefit from access to appropriate community-based or faith-based support. In particular, given the role of faith for many Africans, and growing evidence of the potential negative impact some faith practices may have on HIV clinical outcomes (through treatment adherence) clinics should be recommended to engage with faith leaders and groups, to discuss faith and beliefs with their patients and be aware of these issues.

Discussions around the impact of diagnosis on others, and particularly partner notification, should only take place after screening for actual or risk of Gender Based or Intimate Partner Violence, to ensure the safety of the patient.

We welcome recognition of the disproportionate impact of HIV on already marginalised groups. As well as these factors acting as a barrier to accessing services, specialist services based on these factors are also needed – e.g. individuals who may be subject to immigration detention would benefit from their clinician’s being aware of this fact, to ensure they have adequate treatment supplies in case of detention.

We welcome the broad range of actors identified as important to ensure retention in care – the Standard would benefit from reflection of this in the measurable and auditable outcomes. Too often these broader links are subject to the commitment of individual clinicians, rather than being prioritised in terms of meeting expected standards.